Approaching death: Informed consent and research relationships at the end of life

Marian Krawczyk

Many researchers working with people near end of life are reluctant to discuss the ethical challenges they encounter in fieldwork that includes the biological margins between life and death. In particular, there is an uncomfortable – and little discussed – ethical thicket engendered by ethnographic relationships with participants in the last several days or hours of life, those who are considered to be 'actively' dying. I have shared this reluctance, but increasingly I have come to believe that we must make ourselves professionally and personally vulnerable by publicly offering instances of these ambivalent entanglements. This concern emerges as a product of my dissertation fieldwork. Over a one-year period I conducted research within two large urban hospitals in western Canada, where I observed and/or interviewed 41 palliative and non-palliative clinicians, and followed 36 patients and/or family members through to discharge, or in 70 percent of cases I observed, death. My research interest was to better understand the emotional labour techniques that hospital-based palliative clinicians use to facilitate a good death.

I told all potential participants that I was interested in how meanings and experiences of an advancing life-threatening illness were generated in specialist hospital care over the course of admission, including decisions about treatment. To ensure patients and family members retained control over my presence during this uncertain time, I accompanied the initial formal written consent process with informal verbal consent at the beginning of each interaction and/or observation. I was confident that this ongoing consent process would enable me to successfully navigate any ethical uncertainties in continuing to interact with a patient if, and when, they approached death.

Prognostic uncertainty and the desire to avoid distressing patients with unwanted discussions of mortality are serious considerations in negotiating informed consent in ethnographic palliative care research. While the majority of patients and family members acknowledged the presence of a (potentially) terminal illness, few initially expressed any awareness that their current hospital admission might be their last one. Following the advice of clinicians and my committee, my recruiting and informed consent documents did not indicate that patients may be nearing the end of life or acknowledge that they might die during their hospitalization. Rather I used the seemingly neutral phrases 'advancing life-threatening illness' and 'over the course of your admission'. Still, I found unexpected ethical challenges in not proactively acknowledging that participants might die during the course of their participation, and particularly so as patients approached death.

There were moments where I observed a patient nearing death that continue to leave me questioning the appropriateness of my presence, even though I had secured both written and verbal consent. There were also patients I did not interact with as they neared death, who were no longer able to give verbal consent due to difficulties in speaking, lucidity, and symptom burden. Ostensibly, my bifurcated process of consent was ethically robust. In retrospect, however, I have come to believe the ethical considerations regarding the presence of the researcher in such situations should not only include the participant's capacity to provide consent but should also be informed by the relationships that have developed between the researcher and participant. To ground this claim, I offer the following extract from my field notes about a patient whom I and other clinicians had grown particularly close to.

> Carol [the consult clinician] informs me that Jim will most likely die over the weekend and that if I want to say goodbye that 'this is the time' as 'he is going to change very quickly'. Part of me wants to go in, but I tell Carol that I'm not sure Jim can provide consent as he can no longer speak, and is only partially lucid. Carol then enters his room, ostensibly to check on his status, but in reality to say goodbye. I do not follow her, and she emerges fifteen minutes later, a bit teary. She tells me he looks 'really bad and is becoming increasingly confused', but that he knew that she was saying goodbye and he wrote 'I love you', and burst into tears and everybody was hugging. As I heave a big sigh, she tells me that 'it's OK to cry'.

I did not see Jim again before he died, although I had previously spent a great deal of time with him during his lengthy admission. In the days after his death I told myself that keeping this distance was a sign of professional respect in that I did not believe he had the ability to provide consent. In retrospect I believe my actions stemmed primarily from the inability to say goodbye to someone I cared about. I hid behind my ethical constraints as a researcher to avoid expressing painful 'personal' feelings, and I continue to regret my actions in this instance.

I do not assume Jim thought of me as a friend, nor can I know if he felt abandoned by me. However, we developed affective ties, woven over months during a vulnerable, difficult, and emotionally challenging time. Caring was a significant component of my research relationship with Jim, and in choosing to be constrained by a narrow definition of consent, I was unable to enact that caring with him at the end of his life. From a distal perspective I behaved ethically in defaulting to a formal bureaucratic understanding of consent. From a proximal perspective, I continue to question the personal obligations and social signifiers of ethical research relationships with those near the end of life when they: (1) unfold over a significant period of time, (2) develop within intense affective environments, and (3) evolve to where the participant may no longer be able to indicate ongoing consent.

At the time, I could find no published accounts as to how other researchers have negotiated these moments. I have since been directed to Robert Pool's (2014) description of his ambivalent goodbye with a patient about to undergo euthanasia and to Julia Lawton's (2001) discussion of her uncertainties regarding the validity of consent as hospice patients deteriorate. Both also lament the paucity of published discussions on this topic by other ethnographers. I am sympathetic as to why this may be; even while writing this piece I find myself tempted to minimize the 'messy' aspects in the fear of being perceived as 'doing' ethnography wrong. However, I believe that those of us who do research that engenders affective ties have a moral obligation to each other – and to our participants – to explicitly reflect on our research relationships and informed consent, and especially so when our research encompasses the very end of life. How to best enact that obligation requires publicly discussing our own ambivalent experiences – and hearing others' – of conducting research in intense and vulnerable contexts with those near, or at, the end of life.

Marian Krawczyk, PhD, holds a joint post-doctoral fellowship at the Centre for Health Evaluation and Outcome Sciences and Trinity Western University in British Columbia, Canada. Her dissertation, entitled "Negotiated Practices: Understanding Hospital Palliative Care as an Affective Economy" is the first ethnographic inquiry specific to hospital palliative care in North America. Her current research projects include examining clinicians' use of standardized patient reported outcome measures, charting the history of hospital ethnographies, and using mycelial thinking to map clinical practice innovation. In 2016 she was a visiting scholar with the End of Life Studies Group at the University of Glasgow.

References

Lawton, Julia. 2001. 'Gaining and Maintaining Consent: Ethical Concerns Raised in a Study of Dying Patients'. *Qualitative Health Research* 11, no. 5: 693–705.

Pool, Robert. 2014. *Negotiating a Good Death: Euthanasia in the Netherlands*. New York: Routledge.